



28 FEBRUARY 2021

RAREDISEASEDAY.ORG

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RARE IS **MANY** RARE IS **STRONG** RARE IS **PROUD**

Rare Disease Day is organised by EURORDIS-Rare Diseases Europe and 62 National alliances of patient organisations for rare diseases.

RARE DISEASE DAY 2021

Rare Disease Day was celebrated globally on 28 February 2021 to raise awareness about the experiences of people with rare diseases.

Many people with rare diseases speak of feeling isolated. Many have never met or heard of another person with their condition. If they are the first in their family with the condition, or have a very rare combination, like two bleeding disorders, it may have taken a long time for them to be diagnosed. Women and girls with haemophilia also talk of not being believed because of the common assumption that only males have haemophilia.

When rare diseases are very rare and numbers are small, this can mean that the development of new and highly effective treatments is slow. There may even be no treatment that specifically targets that condition. For example, while there has been great excitement around the world about the novel therapies developed for haemophilia and the difference they make to reducing bleeds and quality of life, there is not yet a specific clotting factor concentrate that is suitable to treat factor V (5) deficiency and fresh frozen plasma may be used for treatment instead.

Following the 2021 theme of **Rare is many. Rare is strong. Rare is proud**, we shared personal stories from our community members in the weeks leading up to Rare Disease Day. This was an opportunity to acknowledge the challenges for our community members who live with a rare disorder and hear what they have learned.

In this issue of National Haemophilia, Belinda tells her story of living with factor X (10) deficiency. <#>

'Rare is many.
Rare is strong.
Rare is proud'